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Written statement* submitted by the European Centre for Law and Justice, a non-governmental organization in special consultative status

The Secretary-General has received the following written statement which is circulated in accordance with Economic and Social Council resolution 1996/31.

[16 February 2015]

* This written statement is issued, unedited, in the language(s) received from the submitting non-governmental organization(s).

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Achieving excellence in perinatal care: babies with illness and disability deserve better than abortion

The Convention on the Rights of Persons with Disabilities states that *'States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children"*. The Convention on the Rights of the Child also states that a child "*needs special safeguards and care, including appropriate legal protection, before as well as after birth*".
Yet studies show that up to 90% of children with disabilities are aborted before birth. In particular, children with life-limiting conditions are subject to discriminatory language and attitudes which deny them their humanity and their human rights.

Discontinuing the phrase 'Incompatible with life'
Unborn children with disabilities are suffering a lethal form of discrimination because they are targeted for abortion, both in law and in practice, simply because of their disabilities. Up to 90% of children with disabilities are aborted before birth. Sometimes the disability is minor and easily correctable such as a cleft palate or a clubbed foot. Other times the baby might have an illness which means he or she may not live for very long after being born. But in all cases these babies are being dehumanized, and their right to life undermined, because they have a physical or genetic disability. This is in contravention of the UN Convention the Right of Persons with Disabilities, which affirms that the right to life of persons with disabilities must be enjoyed on an equal basis with others.

Families who are told that their baby may not live for long after birth need our full support and holistic perinatal care, but this only be achieved if misleading and offensive language and attitudes are discontinued. We are calling to ending the misinformation, which is confusing and hurting parents, and denying children with illness and disability the care they deserve.

The Declaration on Perinatal Care is a global statement from medical practitioners and researchers who affirm that the term, "incompatible with life", is not a medical diagnosis and should not be used to describe an unborn baby who has received a diagnosis which means they may not live for very long after birth.

The Declaration calls for an end to the use of this medically meaningless term which can cause great upset to the parents of children who are given a life-limiting diagnoses but who all too often live for hours, days, weeks and even years after birth and bring much joy to their families. Parents who are told their baby may not live for very long should be offered the full comfort and support of Perinatal Hospice services, before and after birth to help them through this difficult time - and their children are fully entitled to the option of medical intervention for babies who may benefit. Society should recognize that a terminal illness or disability does not diminish the right to life of the child.

Discrimination in law and practice
The UN's World Abortion Policies report 2011 shows that 84% of developed countries permit abortion because the baby has a disability or a 'foetal impairment' and that, globally, almost 50% of countries take this position.
The effects have been dramatic. Studies show that up to 90% of unborn children with disabilities ranging from Down Syndrome to anencephaly have their lives terminated before birth.

A 2013 article published in the *American Journal of Medical Genetics* found that 94% of parents given a diagnosis of Trisomy 13 or 18 were told their baby would not live after birth, although,as we will see, that is not the case with these conditions. 61% of parents said they came under pressure to abort, 55% were told that their child would be a vegetable,

28% that their baby would destroy their family or their marriage. Some parents were told that that their Obstetrician would refuse to continue seeing them if they did not abort.

Fatally Flawed language

It should be noted that the phrase 'incompatible with life' is not a medical diagnosis. A 2012 study entitled *'Fatally Flawed?'* published in the *British Journal of Obstetrics and Gynaecolgy (BJOG)* similarly found that the term 'lethal anomaly' is not a medical prognosis and should not be used in counselling parents facing a diagnosis of severe malformation for their unborn child. The authors, who work in the field of newborn intensive care and in counselling, said that the term hindered clear communication, and should be avoided in counselling. Crucially, they pointed out that "prenatally diagnosed abnormalities that are associated with death in the newborn period are often referred to as 'lethal malformations'. Yet, for many of the commonly described lethal malformations long-term survival is possible if supportive interventions are provided.

In a discussion entitled *'The Language Of Lethality'*, the authors examine the use of the term 'lethal', and consider the published literature, accounts of parents, and their own experience and conclude that "a significant proportion of practitioners do use this or related terminology." They identified several reasons for this:

1. Practitioners may mistakenly believe that conditions [such as Trisomy 18] are not compatible with survival beyond the newborn period.

2. A second potential reason is a discomfort with uncertainty, or a desire to make decision-making simpler. The authors write that "It is potentially easier for women to come to terms with termination of pregnancy or with palliative care if they are told that survival is impossible, and it may be easier for professionals to make and rationalise such decisions."

3. A third possibility is that doctors make a judgment call on the 'quality of life' of another person – has certainly been the experience relayed to us by parents who have faced a diagnosis of a severe abnormality. Parents and their babies deserve better than judgment and a nudge towards abortion.

The authors of 'Fatally Flawed' also found that, having searched the published literature, no agreed definition of a 'lethal fetal or congenital malformation' existed, nor could they "identify an agreed list of conditions that fit into this category".

The study was published just weeks after new research by Dr Anne Janvier of the University of Montreal found that almost all families of children with Trisomy 13 and 18 reported that their time together was happy and rewarding overall. The research, published in the peer-reviewed journal , Pediatrics, found that over 97% of the parents interviewed considered that their child was happy and its presence enriched the life of their family and their life as a couple regardless of longevity.

It should also be noted that the phrase 'incompatible with life' misinforms parents because it denies them full information regarding the condition diagnosed for their child. In contrast to public perception, research shows that children with even the most severe disabilities usually live beyond birth.

A recent study published in the *British Journal of Obstetrics and Gynaecology* found that 72% of babies with anencephaly lived for a short time after birth. Of those children, 25% lived up to 5 days, while up to 7% lived up to 28 days after birth. Studies have found that the average duration of survival for children who lived until birth with Trisomy 18 was 14.5 days; with 39% of babies surviving for more than a month, while 8.4% survived for more than a year. Research has also found that children with Trisomy 13 or Patau's Syndrome live on average for 7 days after birth, while almost 31% live for more than a month, and almost one in 10 live for more than a year.

These conditions are currently being described as 'incompatible with life', words with are medically meaningless, offensive and discriminatory. This declaration aims to discontinue this phrase and to end this lethal discrimination against children, before and after birth, because of a diagnosed disability.

References

Guon J, Wilfond BS, Farlow B, Brazg T, Janvier A. 2013. "Our children are not a diagnosis: The experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18". *Am J Med Genet* Part A 164A:308–318.

Wilkinson D, Thiele P, Watkins A, De Crespigny L. "Fatally flawed? A review and ethical analysis of lethal congenital malformations". *BJOG* 2012;119:1302–1308.

Janvier A, Farlow B, Wilfind *BS. 2012.* "The Experience of Families With Children With Trisomy 13 and 18 in Social Networks". *Pediatrics* 10.1542/peds.2012-015

Jacquier M, Klein A, Boltshauser E. "Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly." *British Journal of Obstetrics and Gynaecology* 2006; 113:951–953

Mitchel L. Zoler, "Trisomy 18 survival can exceed 1 year", *OB/GYN News, March 1 2003 Trisomy 13 / Patau Syndrome*

Rasmussen SA1, Wong LY, Yang Q, May KM, Friedman. "Pediatrics. Population-based analyses of mortality in trisomy 13 and trisomy 18". *2003 Apr;111(4 Pt 1):777-84 JM.*

Wu J, Springett A, Morris JK. 2013. "Survival of trisomy 18 (Edwards syndrome) and trisomy 13 (Patau Syndrome) in England and Wales". *2004–2011. Am J Med Genet Part A 161A:2512–2518.*

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*Every Life Counts, Ireland, an NGO without consultative status, also shares the views expressed in this statement.